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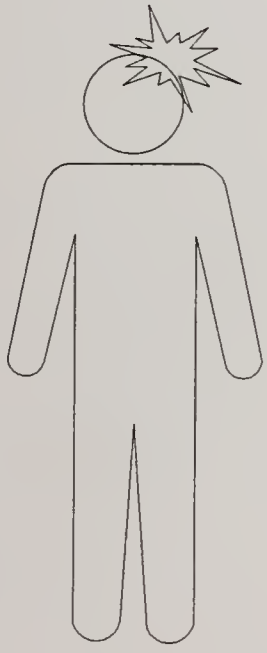
MEDICAID SERVICES SURVEYS

HEAD INJURIES IN MONTANA

HOSPITALS AND NURSING FACILITIES



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DEPARTMENT OF
SOCIAL AND REHABILITATION SERVICES

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October 30, 1992

TO: Interested Persons

FROM: Nancy Ellery, Administrator
Medicaid Services Division

I am pleased to present the results of a survey conducted by Cecilia Cowie of our staff regarding individuals with traumatic brain injuries.

There is an increasing concern about the provision of appropriate services to persons with traumatic brain injuries and their families. Our agency receives many requests for services which we are unable to address. We are trying to better understand what services are needed and who needs them.

The data in this report relates the information we received. While it is limited, it gives us a basis from which to begin discussions within our agency and with others.

To those of you who took the time to complete the survey, we thank you. To those of you who have a personal or professional interest in individuals with traumatic brain injuries, I encourage you to be in contract with Ms. Cowie at 444-4150 to relate your concerns.

*"The mission is to change public policy to prevent traumatic brain injuries, empower persons with those injuries, and assist them to live independently, participate fully in life, and be treated with dignity".**

* Rocky Mountain Regional Brain Injury Center

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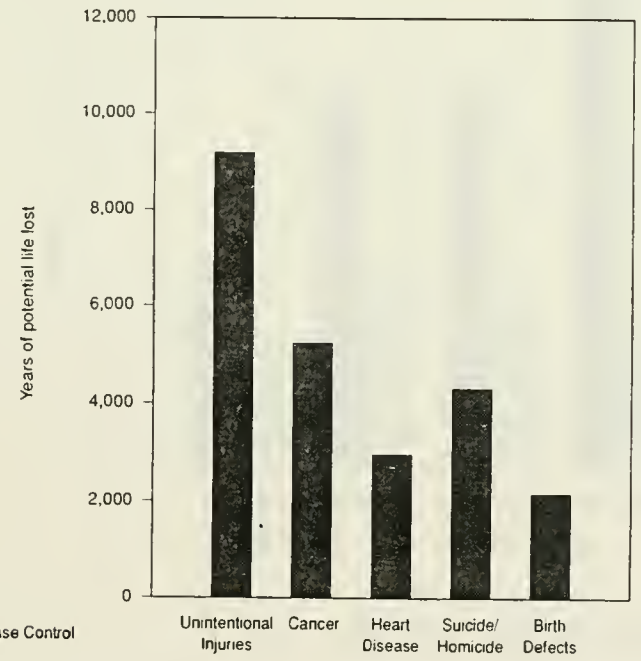
Head Injuries in Montana

Every fifteen seconds someone sustains a traumatic brain injury (TBI) in the United States. Every five minutes one dies and another becomes permanently disabled. Of the two million Americans who sustain a TBI annually, two-thirds are under the age of 34. A survivor of a severe brain injury typically faces five to ten years of intensive services at an estimated cost in excess of $4 million.[1]

BACKGROUND

Injuries and disabilities are the leading cause of preventable death, lost productivity and social dependence. Frontier states

Table 1. Leading Causes of Years of Potential Life Lost Before Age 65 Montana, 1988

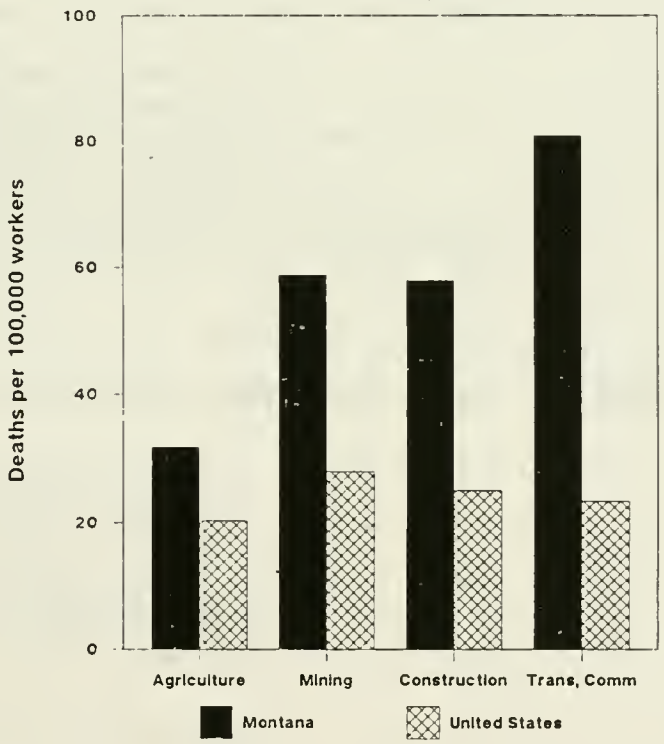


Source: Centers for Disease Control

[1] Statistical information provided by the National Head Injury Foundation and MPS Associates, Inc.

such as Montana have higher rates of injuries than other states. The primary occupations in Montana (agriculture, timber and mining) are among the most dangerous of all occupations. Montana also has a high rate of substance abuse related accidents resulting in head injuries. Motor vehicle crashes cause one-half of all traumatic brain injuries. Child abuse accounts for 64% of infant head injuries. Traumatic brain injury is the leading killer and cause of disability in children and young adults.[2]

Table 2. Workplace Death Rates for Select Industries
Montana and United States
1980 - 1986



Source: Centers for Disease Control

[2] Ibid.

THE SURVEYS

There is much interest and concern regarding the service needs of survivors of TBI. In a first attempt to shed some light on the problem in Montana, surveys were mailed to nursing facilities and hospitals to obtain data on the incidence and prevalence of persons with TBI in these two settings.

Hospital Surveys

Surveys were mailed to 56 Montana hospitals. 30 completed surveys were returned from which the following data was gleaned:

Total number of persons treated as in-patients for head injuries in the year 1991:	565

Health Coverage of head injured patients:

Patients covered by Medicaid	115
Patients covered by Medicare	110
Patients covered by private insurance	191
Patients covered by Champus	5
Patients covered by State Medical	11
Other (patients covered by Indian Health Service, foreign insurance, or having no insurance)	133

Upon discharge from the hospitals, these patients went:

Home with services	27
Home without services	415[3]
To a group home	3
To a nursing facility	36
To another in-state hospital	34
To an out-of-state hospital	1
Other	26
Number of Deceased patients	23

[3] One hospital did not distinguish between those patients who went home with services and those who went home without services. Therefore the 63 patients they reported as being discharged home were included under the home without services category.

Head Injuries in Montana

Nursing Facility Surveys

Surveys were mailed to **100** Montana nursing facilities. **60** completed surveys were returned from which the following data was gleaned:

Of the **60** nursing facilities that responded, **19** had residents with TBI. Of these, **2** had a special wing or section of the facility for their residents with head injuries.

Responses to whether their TBI residents exhibited severe behavior problems:

Yes:	**8**
No:	**11**

Responses to whether staff can handle these behavior problems:

Yes:	**10**
No:	**4**
N/A:	**5**

Responses to whether facility uses outside consultants, services, or specialists to help in care of TBI residents:

Yes:	**10**
No:	**9**

Responses to why residents with TBI were not living in the community (facilities were allowed to check more than one response):

Their medical condition is too severe:	**16**
Their behavior problems are too severe:	**8**
No financial resources for community living:	**6**
No community support systems available:	**6**

Responses to whether nursing facility staff receives special training on how to handle residents with TBI:

Yes:	**9**
No:	**10**

Responses to whether such training was necessary:

Yes:	**14**
No:	**3**
N/A:	**2**

Head Injuries in Montana

Total number of individuals with head injuries **currently residing** in Montana nursing facilities:

50 individuals

Age Categories:

Number of individuals in their teens:	1
Number of individuals in their twenties:	8
Number of individuals in their thirties:	11
Number of individuals in their forties:	11
Number of individuals in their fifties:	5
Number of individuals in their sixties:	8
Number of individuals in their seventies:	3
Number of individuals in their eighties:	1
Number of individuals in their nineties:	2

Number of individuals admitted from:

An acute care hospital	14
A rehabilitation hospital	15
Home	7
A group home	2
Another nursing facility	10
Other (Jail, Boulder)	2

Coverage of individuals with TBI in NFs:

Medicaid	30
Medicare	6
Private Insurance	14

CONCLUSION

The information gathered through the surveys gives us a small piece of the service puzzle for persons with head injuries. Individuals admitted only to the emergency rooms of hospitals were not included in this count. Others omitted, may have been individuals who did not have a primary diagnosis of head injury.

The real challenge for service providers often comes after acute rehabilitation.

With the advances in medical technology an ever increasing number of individuals are being kept alive, rehabilitated and returned to the community.

Survivors of TBI require a number of services. Aside from the immediate care, acute care, and acute rehabilitation, persons surviving a traumatic brain injury often require long term post acute care and services. Post acute care can be provided in a nursing facility, other residential setting, or the individual's home.

What happens to survivors of TBI upon discharge from an acute care hospital varies. Each individual and injury is different. Ideally, individuals being discharged should have a number of options available to them depending upon where they are in the recovery sequence.

In Montana, only one nursing facility provides extended head injury nursing care with specialized services for persons with head injuries. Supported apartment living and supported group living are available on a limited basis through the Developmental Disabilities Division to those individuals who qualify (must meet developmental disability (DD) definition, i.e., mental retardation (MR) or related condition acquired before the age of 18). Our Home and Community Services Waiver serves some individuals with head injuries in the two group homes for the physically disabled we have in Missoula.

Individuals returning home from a rehabilitation center can receive out-patient services such as physical, speech, occupational therapies, and psychological counseling. Some independent living centers offer independent living skills training and one center offers substance abuse support groups for their clients with head injuries. The Montana Head Injury Association has support groups throughout the state for individuals with head injuries and their families.

Head Injuries in Montana

A number of gaps exist in the comprehensive continuum of care in Montana; for example, widespread specialized TBI nursing care, specialized day programs (cognitive rehabilitation programs), specialized chemical dependency programs, more assisted living alternatives, and supported employment for persons with head injuries. Post acute in-patient rehabilitation is a critical and lacking service for persons with head injuries. Repercussions from head injuries often last a life time. Secondary disabilities, severe behavioral, psychological, and social malfunctions as well as substance abuse, can surface throughout a survivor's life time and appropriate interventions for these must be made available.

Many survivors of TBI, because of a lack of financial resources or a lack of available services, still fall through the proverbial cracks. Some are served by mental health centers. Others end up in prison, in Warm Springs, or in nursing facilities without appropriate services. Still others end up on the streets and are counted as transients or homeless. Fortunately, there is a movement on the national level to improve the lives of survivors of TBI.

Policy, legislation and funding are three of the keys to opening the gate to adequate services for persons with head injuries. Today, only one in twenty people with TBI receives necessary rehabilitation services. Tomorrow, it could be twenty in twenty.

Following are excerpts from articles written by people who have sustained a traumatic brain injury. These often powerful anecdotes of survivors take us into the personal world of living with such a disability.

Tragic Summer[1]
Rich Troth

"My most memorable summer was when I was 18 and coming home from college in my 1966 Ford Mustang. I had been drinking at a party and was speeding to get home quickly. As I got close to home near Eddy's Corner, I fell asleep, had an accident, and hit my head on the windshield as I was thrown from the car. This was my most memorable summer because it changed my life forever. I never did graduate from college because of this summer."

The Voice of Experience[2]
Dan Kardokus

"In my case, I was hit by a hit and run driver at 2 a.m. on July 13, 1986. The people who witnessed the accident did not realize they were watching a man being hit. I laid in a ditch for six hours. I became aware of my surroundings two weeks later and was hospitalized for 32 days.

The first month after the accident, everyone was concerned and supportive. Then the disability became "old" for family and friends. I was experiencing post traumatic depression and people went to our new pastor asking, "What's wrong with Dan?" No one had told us about the severe memory loss I was experiencing.

Although my employment was completely supportive emotionally and somewhat financially, no work meant no pay. I could not draw worker's compensation. It was hit and run so there was nobody to pursue, no money was available. "Victims of Violent Crime" came through in January. I had a four-year-old son and ten-month-old daughter.

The social services counselor told us we had two options: either I had to be declared disabled (which was in process), or we had to break up. Luckily the Texas Institute of Research and Rehabilitation helped overrule the counselor but it took months.

My wife began to feel everything centered around me. She had needs too. The marriage did not survive.

Social Security denied me the first time. I wondered if the disability was all in my mind.

Ninety percent of all marriages in which one partner has TBI end in divorce. In the midst of this turmoil, fear, isolation, and bewilderment, family members and friends are invaluable.

Independence is difficult. The spouse, parent, child or sibling becomes the primary care giver. It then is very difficult and threatening to allow the injured person to take control of his/her own life. No one wants to see that person struggle and make mistakes. But its a long journey back. It is hard for those around the survivor not to expect that one success guarantees continued success. But how can a person truly become independent without the normal ups and downs of life?

There is a fine line between assisting a person in regaining balance and hampering the individual's personal rights. A person has the right to fail.

I personally began trying to figure out my own limitations, creating a conflict. I was concerned about job skills, like filling out forms. My spelling had become a nightmare and I found myself writing words that had no rhyme or reason.

I desperately wanted to learn how to handle stress. The voc rehab counselor gave me a "rosy picture" and a lot of promises. The doctor kept saying that he was going to get my job description so we could work on "necessary skills". (It wasn't until I had completed a semester at college that we discovered I was in the 4th percentile in reading rate and the 11th percentile in comprehension.) Imagine the frustration when professionals kept telling me what they could do for me and never followed through. When the doctor learned I had enrolled in college, he wrote, "I regret Mr. Kardokus' decision because he will probably fail."

My voc rehab counselor was there for me. "Dan, if you have to drop out of school, realize you've come further than anyone expected you to." But he never told me to give up. He was as happy as I was when I received a 3.7 GPA.

It is vital, as you work with persons with disabilities, to be there with them. I have made some serious blunders in the last six years, but the support was there. A lot of people do not have these support systems.

It is important to know this. The survivor may be bitter and reluctant to open up, yet desperately wanting someone to understand.

Testing may not show a person's capabilities, especially if he is stretching himself. Sometimes survivors are not aware of their problems and need someone to help them organize their problem solving techniques.

> Brain injuries almost always have an immediate adverse effect on an individual's performance of everyday tasks. Emotional functioning is often changed by brain injury. Depression is a frequent problem, resulting from actual brain damage and loss of function, income, and

social abilities. A person with a brain injury may have trouble stopping an emotional reaction, such as anger. Often the brain injury survivor cannot help his or her behavior.

• • •

How can I really help the TBI survivor?

1. Be concrete. Many people lose the ability to think abstractly. Never ask hypothetical questions.

2. Be concise and to the point in explaining things. A TBI survivor may retain 3 or 4 things at one time. Normal is 7.

3. Write instructions. Verbal information gets forgotten or scrambled.

4. Give the person time to collect their thoughts. Sometimes a thought is lost mid-sentence. Allow the person time to reorganize.

5. Be patient, even if the survivor repeats himself.

6. Be punctual. TBI survivors have difficulty handling changes in routine.

7. Allow additional time when transporting a survivor. A TBI survivor will often panic when late for an appointment.

8. Fatigue sets in in the afternoon. Cognitive processes may collapse. Mornings are better.

9. Anger! There are two things to note here. First, the normal ways of handling anger may be outside of a survivor's grasp; and two, there is no fuse. The survivor is often unaware of the anger until s/he explodes. It is important for those around him/her to help them work through their anger.

10. Because TBI is a hidden disability, survivors often suffer yet do not have any validation of their disability. Take time to listen.

What is the hardest thing
to cope with now?

Never being able to be
sure of yourself again.

There are times when the need to have someone to listen, to cry with, to hear the fear and bewilderment, is so important. It

is true that every injury is unique and every person has to face their challenges the best way they can; but it helps if a doctor, a friend, a therapist, a rehab counselor, or a family member, can just listen, without judgement, and let the survivor know they are there to hold their hand when needed. I hope I have, in some small way, contributed to that understanding. I want to let survivors know they are not alone."

Summer Pastimes[3]

Lorry Atkins

"The first thought for me about summer is recreation and travel. I used to love the outdoors. I still do, but now I don't get out as often. Hiking, picnicking, swimming, climbing mountains and rafting used to be favorite summertime activities for me. Now I just observe others in their summer activities. I did quite a bit of boating on Flathead Lake. I used to like hiking under waterfalls. You really can't know what that is like unless you do it.

I still love the summer, particularly going on scenic drives, sitting in the sun, having barbecues and going to local parks. So when someone asks me what I like about summer, I say "getting out in the outdoors."

1.Published in Expressions, Newsletter of Adult Day Services, Opportunity Resources, Inc., Missoula, MT.; October, 1992.

2.Published in Brain Scan, Newsletter of the Rocky Mountain Regional Brain Injury Center, Denver, CO.; June, 1992.

3.Published in Expressions, Newsletter of Adult Day Services, Opportunity Resources, Inc., Missoula, MT.; October, 1992.